

1. Summary of the NLTCS

The Center for Demographic Studies, Duke University, is currently planning to conduct the 2004 National Long Term Care Survey (NLTCS) later this year. The 2004 survey will be the sixth time the NLTCS has been conducted. Previous surveys were conducted in 1982, 1984, 1989, 1994, and 1999.

The NLTCS collects information on Medicare recipients who are 65 years of age or older with emphasis on the aged population who are functionally impaired. As with prior surveys, the 2004 NLTCS sample has a longitudinal component and an aged-in component. The longitudinal component consists of about 13,300 people who responded to one or more of the previous five surveys. The aged-in component consists of 5,600 who turned 65 years old since the 1999 survey. An additional 1,000 people who are 95 years of age or older will also be drawn. The total sample size is about 19,900. About 1,800 of the total sample are in the healthy supplement.

The NLTCS consists of a screener interview to determine if a person is functionally impaired or currently living in a nursing care facility. If the person is functionally impaired and living at home, he/she is administered a community interview. If the person is in a nursing care facility, he/she is administered an institutional interview. If the person is selected as part of the healthy supplement, he/she is given an abbreviated version of the community interview.

We will also conduct a caregiver supplement to the NLTCS. During the community interview, we collect information on people who provide help or assistance to the NLTCS respondents. For the caregiver sample, we select the helper, if any, who has provided the most help to the NLTCS respondent.

The NLTCS samples are randomly selected from Medicare beneficiary enrollment files which are nationally representative of both community and institutional residents. As sample persons are followed through the Medicare record system, virtually 100% of cases can be longitudinally tracked so that declines, as well as increases, in disability may be identified as well as exact dates of death.

NLTCS sample persons are followed until death and are permanently and continuously linked to the Medicare record system from which they are drawn. Linkage to the Medicare Part A and B service use records now extends from 1982 to 2002, so that detailed Medicare expenditures and dates and types of service use +(including ICD-9 diagnoses) may be studied. Through the careful application of methods to reduce non-sampling error, the surveys provide nationally representative data on:

- The prevalence and patterns of functional limitations, both physical and cognitive;

- Longitudinal and cohort patterns of change in functional limitation and mortality over 20 years;
- Medical conditions and recent medical problems;
- Health care services used;
- The kind and amount of formal and informal services received by impaired individuals and how it is paid for;
- Demographic and economic characteristics like age, race, sex, marital status, education, and income and assets;
- Out-of-pocket expenditures for health care services and other sources of payment;
- Housing and neighborhood characteristics.

In the 2004 NLTC we have implemented the following changes,

Respondent Identification: For each section of the questionnaires, we will identify whether the sample person or a proxy respondent answered the questions. This is important in data assessment. For example, the level of help needed that is reported by an individual is usually less than the amount of help reported by a caregiver. This identification was not done in previous surveys.

Screening Questionnaire: The activities of daily living (ADL) and the instrumental activities of daily living (IADL) will be administered to all noninstitutional sample people. Previous NLTC surveys did not ask people in the longitudinal sample about disabilities during the screener. This created some problems with establishing disability at the time of the screener for weighting purposes.

The screener was expanded to include the new race and ancestry questions developed by the Census Bureau for its demographic surveys and several other questions like educational attainment, marital status, and veterans status. This change consolidates many of the demographic variables in the screener and provides statistics more consistently for the entire sample.

Control Card: The format of the control card will change to accommodate interviewing in an institutional setting. In addition, the control card will collect information on the number of hours worked by the sample persons' children and their spouses. These questions were asked in the 1994 survey but were excluded from the 1999 survey. The caregiver research community uses this information to determine the potential caregiver universe.

Community Questionnaire: The length of the community interview will be shortened by replacing the lengthy cognitive assessment section used in 1999 with the shorter section used in the 1994 survey. In addition to this change, questions in other sections were modified or eliminated in order to reduce the overall length of the survey.

Institutional Questionnaire: The institutional interview will be changed to allow

the sample person to have greater participation than in previous years. If the sample person is not capable of participating due to physical or mental impairment, the sample person's family will be asked to play a larger role. In prior surveys, most of the information was obtained from the nursing home staff resulting in incomplete data for many of the cases. Also, the list of medical conditions asked in the community interview will be asked in the institutional interview.

The caregiver selection: The caregiver selection criteria will be modified. In previous caregiver surveys, some caregivers were excluded from selection based on conditions defined in the selection process which are now believed to have been overly restrictive.

2. Status of the project

This is an ongoing project. Currently, the Center for Demographic Studies is in its 17th year of work on this survey. Funding has been extended through project year 18.

3. <http://nltcs.cds.duke.edu/index.htm>

4. Keywords

Long Term Care
Functionally impaired
Physically impaired
Cognitively impaired
Disabled
Medicare
Activities of Daily Living
Instrumental Activities of Daily Living
Medical Conditions
Health Care Services
Institutional
Community

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6. Additional details of the study

The CDS is also planning to collect biological specimens from 5600 participants in the 2004 NLTCS referenced above. The objective of these studies is to increase the body of knowledge regarding the heritability of disability and disease in the elderly. The functional goal of this study is to expand our existing genetic database of 2700 elderly collected in 1999, for use as a resource for data-driven scientific decision and policy making. We plan to use the 1999-2004 data to examine the role of genetics in chronic diseases and longevity.

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